

Stories of Hope - Sickle Cell Disease



For the first nine months of Joseph Katambwe's life, everything was perfect. Then one day he started crying and could not stop.

"He could not be comforted," said his grandmother **Nancy Rene**. It was his first brush with the ailment he was diagnosed with before birth, sickle cell disease. His father, whose younger brother also had sickle cell, recognized the signs, and the parents rushed their baby to the hospital. When Rene saw the baby later that day, he was still crying and slapping at the oxygen tube in his nose.

"I remember the tubing, and he hit it with both hands. He didn't like it. The next day, he hit it with only one hand. He would cry, and only his left side was moving." By that night it was confirmed, Joseph had suffered a stroke.

Nine years later, Joseph's right side is still a little weak, and the 9-year-old wears a leg brace on that side. But, Rene says, "Being a little boy trumps having a stroke."

"He runs as fast as other kids; he rides his two-wheeler," she says. And every six weeks, he goes in for a blood transfusion. "He really does not cry. He understands this is thing in life."

Bone marrow transplants have cured sickle-cell patients with matching donors. "That's a wonderful thing," Rene says. She looks forward to a day when stem cell treatments will be possible in children without a matching donor – work now under way in the lab.

"This research is something that can really make difference in the lives of kids and families and I certainly cannot thank you enough for making it happen," she says.

- Watch talks from the spotlight on sickle cell disease
- Read more about CIRM funding for sickle cell disease research